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# Personal identity and the role of ‘carer’ among relatives and friends of people with multiple sclerosis



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## ABSTRACT

Informal caregiving continues to be a crucial part of health and social care provision in the developed world, but the processes by which the identity of informal caregiver is conferred, or assumed, remain unclear. In this article we draw on data from a qualitative research study which examined the experiences of family members and friends of people with multiple sclerosis (pwMS) to explore how they interpret the label ‘carer’. We conducted narrative interviews with forty people throughout the United Kingdom between June 2011 and January 2012. Participants were spouses, partners, parents, children, siblings or friends of people who have had multiple sclerosis between 6 months and fifty years. We carried out thematic analysis of the interviews, informed by identity theory. Identity theory illuminated variation in peoples’ perceptions of themselves as carers, suggesting that self-identification with the role and label of carer is nuanced, shifting and variable. We propose a taxonomy of caring activity including emotional support, personal care, physical care, household tasks, advocacy and activism and describe four categories, with fluid and overlapping boundaries, in which the identity of carer was apparently embraced, enforced, absorbed or rejected. Variability and fluidity in self-identification as a carer are related to apparent expectations about whether one *should* assume a caring role. Those who were caring from the more tangential (and less taken for granted) relationship of sibling or ex-partner were among those who apparently embraced the role. Those who were expected to assume the caring role (typically spouses) were not always comfortable with doing so. It may be difficult to gain acknowledgement from family members and others that they occupy the role of carer if people resist the label as a bureaucratisation of their personal relationships.

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## Introduction

The words ‘carer’ or ‘caregiver’ are commonly used to describe a person who gives significant amounts of help over long periods of time to a relative, friend or neighbour who is ill or disabled. This ascribed role is deemed important economically, saving billions of pounds that would otherwise have to be spent on health and social

care services. As a measure of this importance, there has been a campaign in the UK to give the word ‘carer’ protected status (Lloyd, 2006), whereby its use would be confined to describing the activity of so-called ‘informal care’ as opposed to health and social services supplied by paid workers.

The challenges, and potential rewards, of informal caregiving in the developed world have been documented in international literature over many years (Archbold, Stewart, Greenlick, & Harvath, 1990; Nolan, 2001; Robinson, 1983; Schumacher, Stewart, & Archbold, 2007). Studies in Canada, the United States and Australia suggest that the role of informal caregiver is disproportionately occupied by women and is seen to have negative effects on their health (Calasanti & King, 2007; Guberman, Maheu, & Maillé, 1992; Lee & Gramotnev, 2007; Lee & Porteous, 2002). In spousal caregiving relationships, the impact of ‘caregiver burden’ is affected, across Western societies, by the quality of the relationship within the couple (Badr, Acitelli, & Carmack Taylor, 2007; Boeije, Duijnste, & Grypdonck, 2003; Boeije & van Doorne-Huiskes, 2003; Coeling,

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Biordi, & Theis, 2003; Schumacher et al., 2007; Starks, Morris, Yorkston, Gray, & Johnson, 2010) and by the extent of family and other support networks (Bowen, MacLehose, & Beaumont, 2011; Neufeld & Harrison, 2003).

In most European countries it is still assumed that unpaid work by informal carers will supplement formal care provision (Triantafyllou et al., 2010, p. 43). In the United Kingdom, for more than two decades campaigners, policy makers and researchers have attempted to make visible a supposed hidden population of carers, usually reported to be around 6 million people, to identify their needs (Arksey & Glendinning, 2008; Soothill et al., 2001), understand their experiences across a wide range of conditions (Kraijon, Brouwer, de Leeuw, Schrijvers, & van Exel, 2011; McLaughlin et al., 2010; O'Brien, Whitehead, Jack, & Mitchell, 2012; Olson, 2011) and implement policies that will enhance their support. There is particular concern to identify and support young carers (Smyth et al., 2011).

Since the publication of the National Carers Strategy in England (DOH, 1999, 2010) there have been renewed efforts to identify and support carers (Jones, Mackenzie, Greenwood, Atkins, & Habibi, 2012). This is an ongoing process which some feel needs the force of legislation, though a Private Member's Bill in the UK House of Commons, designed to enhance the identification and support of carers, failed to make parliamentary progress (Carers Identification and Support Bill, 2010–12, [www.parliament.uk](http://www.parliament.uk)).

A widespread finding in research with informal carers is that many people do not identify with the term 'carer' because they perceive their helping activities as a normal part of the relationship that they have with a person who is ill or disabled (Bowen et al., 2011; Henderson, 2001; Molyneaux, Butchard, Simpson, & Murray, 2011; O'Connor, 2007; Smyth et al., 2011). Molyneaux et al. (2011) go so far as to suggest abandoning use of the term 'carer' altogether. They examine literature in various 'caring contexts' — mental health, palliative care, older adulthood and dementia, physical and intellectual impairments — and argue that there has been 'consistent failure of the term 'carer' as a recognisable and valid description of the relationship between 'carers' and those for whom they care' (p. 422). They also argue that use of the term may imply burden (indeed the phrase 'carer burden' is common in the literature) leading to a devaluation of the individual who is cared for. In such circumstances the reciprocity and mutuality which is seen to characterise many relationships between caregiver and cared for (Nolan, 2001) may remain under-acknowledged. Molyneaux et al. (2011) conclude that 'descriptions of the caring relationship that focus on the relationship from which it arose would be both more acceptable and useful to those it concerns' (p. 422).

### *Multiple sclerosis*

Multiple sclerosis (MS) is an inflammatory disorder of the central nervous system (CNS). It is characterised by lesions and scarring of the protective myelin sheath of CNS neurons, leading to neuronal damage and axonal loss (Burgess, 2002; Keegan et al., 2002). The course of the disease is uncertain but as it progresses the person with MS may face physical problems including muscle weakness, impaired use of limbs, spasticity, bladder and bowel dysfunction, sexual dysfunction, problems with speech and swallowing and visual difficulties (Schapiro, 2007). There may also be hidden difficulties such as fatigue, dizziness and pain and, as the disease advances, cognition problems such as short-term memory loss, lack of personal insight or forward planning and mood swings (Burgess, 2002).

Approximately 85% of people with multiple sclerosis present with the relapsing-remitting form, characterised by episodic

relapses and remissions that may be partial or complete (Murray, 2006). Usually after around 10 years, about half of people with relapsing-remitting MS will go on to develop secondary progressive MS, where symptoms gradually worsen and there are fewer or no periods of remission. Progression from onset affects around 15% of people diagnosed and is defined as primary progressive MS. In this type, symptoms gradually get worse from the outset and there are few or no periods of remission. Fifteen per cent of people with relapsing-remitting MS have a mild course with minimal disability after 15 years, called 'benign' multiple sclerosis (Murray, 2006).

### *Caring and identity*

In this article, drawing on a study of 40 relatives or friends of people with MS, we explore ways in which people presented and talked about their identities in relation to a person with multiple sclerosis (pwMS) and the extent to which they identified with the term 'carer'. We interpret our findings from the perspectives of identity theory, particularly as explicated by Stryker and colleagues (Stets & Burke, 2000; Stryker & Burke, 2000).

Social scientists have theorised about identity in at least two parallel strands, rooted in and expanding the seminal theoretical work of Erikson (Schwartz, 2001) and elaborating on GH Mead's ideas about the relationship between self and society (Stryker & Burke, 2000). Identity theory focuses on the roles people occupy (what one does) as the basis for identity, while social identity theory emphasises social structure, or group belonging (who one is) as a source of identity (Brown, 2000; Stets & Burke, 2000; Stryker & Burke, 2000). These two theoretical approaches are increasingly convergent in some views (Stets & Burke, 2000) and it is widely acknowledged that people have multiple identities, grounded in the occupancy of multiple roles and diverse group memberships. Multiple identities may reinforce or conflict with each other (Stryker & Burke, 2000).

Role-based identities appeared to be more common than group-based identities among participants in the study reported here, though it should be noted that there is overlap between roles and categories and that people frequently (inevitably) occupy roles at the same time as participating in membership of social categories (Stets & Burke, 2000). In the present context, for example, 'carer', 'husband/wife/partner/spouse', 'son', 'sister', 'best friend', are all at the same time instances of roles and categories.

## **Methods**

### *Sample and recruitment*

We conducted 40 narrative interviews with people who self-identified as a relative or friend of someone with multiple sclerosis. A diverse sample of participants was recruited through newspaper adverts, carers' groups, posts on MS charity websites, and (in a few cases) by snowballing through existing contacts. Following initial contact with the research team to express interest in taking part, potential recruits were mailed a detailed Participant Information Sheet and a personal details form, which they returned to the research office in a pre-paid envelope. They were then contacted by phone in order to answer any queries about the study, to confirm agreement to participate and to arrange the interview. Written consent was gained at the time of interview. The study was approved for multi-site recruitment by the Berkshire Research Ethics Committee.

We sought a maximum variation sample (Coyne, 1997) in order to capture a wide range of different experiences. Thus, we interviewed 19 men and 29 women, aged 17–75, who were spouses/partners (27), siblings (2), children (5), parents (4) and friends (2) of

people with MS. Participants were from a range of socio-economic and ethnic backgrounds. They lived in a variety of locations across England, and one in Scotland. Twenty-eight participants lived with the pwMS. Ten of the people with MS had relapsing-remitting MS, 24 had secondary progressive MS and six had primary progressive MS. One participant was interviewed in the presence of the pwMS and two participants, related to the same pwMS, were interviewed together. Thirty-eight interviews were conducted in participants' homes. One interview was conducted at the participant's workplace and one, because of difficulty arranging a convenient time to meet, owing to her work commitments, was self-recorded by the participant following a written interview schedule mailed to her by the first author (NH). Interviews were conducted between June 2011 and January 2012.

#### Data generation and analysis

Interviews were audio or video-recorded, with participants' consent, for later use on a health experiences and information website ([www.healthtalkonline.org](http://www.healthtalkonline.org)). All interviews were conducted by the first author and transcribed verbatim. Interviews began by inviting participants to talk about their experiences of MS from the point in time when the illness became apparent in their relations with the pwMS. During this part of the interview the researcher listened without interruption, unless the participant came to a halt and asked for prompting to resume their account. When the participant finished speaking the interviewer went on to ask two types of questions: i) questions which sought greater detail on a topic already spoken about; ii) questions on topics which had not been covered, but which we knew from the literature that we wanted to hear about; for example, experiences of paid-for-care, impact of MS on personal and family relationships. Interviews lasted between 20 min (self-recorded audio) and 2 h 15 min, with an average length of approximately 65 min.

Interview transcripts were returned to participants for review and to remove anything they did not wish to be used on the health experiences website. Final transcripts were uploaded to NVivo9 for coding. The narrative structure of the interview formed a basis for initial coding. That is to say, most people began with an account of the first time they and the pwMS noticed symptoms which ultimately contributed to the diagnosis of MS. They talked about their perspectives of the process of visiting the GP, being referred to a neurologist, having investigations, receiving a diagnosis, having treatment and how they, and the pwMS, reacted to all these experiences.

Codes were also identified based on emergent topics which had not been anticipated; for example, participants taking on roles of advocate and activist on behalf of people with MS. This article draws on a thematic analysis of coded interview data, conducted by NH, in which participants spoke in detail about 1) the tasks they undertook to support their relative or friend with MS and 2) the extent to which they identified with the term 'carer'. LL reviewed the analysis, in the role of research 'buddy', and proposed an interpretive framework for the article. NH drafted the manuscript, with substantial input to ideas and structure from LL and SZ. Participants are referred to by pseudonyms in all interview extracts.

## Results

### Caring tasks

Participants carried out a wide range of tasks in support of their relative or friend with MS (see Table 1) extending from emotional support through a wide range of physical and domestic assistance to political activism. Most discussed giving support willingly but

there could be tension and stress, especially where a lot of support was needed or there was a clash of expectations between participants' needs and wishes for their own life and the needs for support of the pwMS. This appears to be related to the nature of the relationships and the perceived expectations about obligation to fulfil the caring role. One man said, for example, that he 'resented' the effort and expense of providing care for his wife. 'Why couldn't I live a normal life like everybody else? The thing that got me the most is not to be appreciated for what I do, I don't mind doing it but I want a bit more appreciation and respect for what I do' (Jan, age 56, spouse with secondary progressive MS).

Some participants described how it was important that they give emotional support to their relative or friend with MS. In addition to doing extra domestic chores, Derek described himself as a 'cheerleader' to keep his wife's spirits up. Andrew talked about supporting his wife emotionally as well as physically. When Cordelia's friend lost bladder control in a public place and was embarrassed she thought that she helped him most by 'comforting' him to ease his embarrassment and sense of humiliation. Giving emotional support to a pwMS could mean putting your own needs second. As teenagers, Andrea felt responsible for supporting her mum when she got upset that her MS was getting worse and Nicole talked about 'buffering' her mother's emotions. Evelyn gladly gave emotional support to her newly diagnosed husband but also felt in need of emotional support herself.

Where physical help was needed some people were able to share household jobs, dividing them up on the basis of what the person with MS still wanted to do. Barnaby and Patrick did all the cooking and shopping; their wives with MS continued to do washing, ironing and some cleaning. This suggests an interdependent relationship rather than a caring/cared for division. Some people talked about having to 'do everything,' but this could mean different things. For example, Karen and Richard did the domestic jobs, but their partners did not need help with washing and dressing; Laura's husband needed help with fastening buttons but otherwise could dress himself. Melvyn called himself a 'full-time carer', because he felt that his partner needed him to be with her all the time, but they also had paid carers to help her get up, washed and dressed.

For some people MS had led to profound disability and the need for much more help with everyday living. Edward, Terry and Peter all talked about their wives being fully dependent on them as their mobility and ability to care for themselves had become severely restricted. In each case paid carers visited at least once a day to help with washing, dressing, getting out of bed and putting to bed. But during the day these men still needed to give a lot of physical and practical support to their wives. Edward noted that 'you don't think it's going to, but it affects your whole life.' Terry observed that a 'carer's life develops over the years' and that now

**Table 1**  
A taxonomy of caring.

Task	Example
Emotional support	Being strong, putting own needs second 'because it's worse for the pwMS' 'Cheerleading' and lifting spirits
Personal care	Help with washing, dressing, eating, using the toilet
Physical care	Help with walking, lifting, hoisting
Household tasks	Shopping, cooking, cleaning, setting table, carrying plates, gardening
Advocacy	Co-ordinating the contribution of paid caregivers including monitoring quality of care and conflict resolution Power of Attorney
Activism	Formal roles in MS or carers' groups Political campaigning Establishment of support groups

they had got to a stage where his wife ‘lives her life through me.’ Peter put his own back at risk by continuing to lift his wife into her wheelchair so they could still go out together. He acknowledged the potential harm to himself but said ‘it’s a price I’m willing to pay because I want to have a life with my wife, I don’t want to be a carer.’

Some participants described taking on the roles of ‘advocate’ or ‘champion’ for a pwMS whose physical care needs were being met by paid carers. Peter co-ordinated the input to his wife’s daily care by paid caregivers and when he thought the care was unsatisfactory he initiated and pursued a formal complaint to the care provider. Such ‘advocates’ did not always live with the pwMS. Alice’s former partner, still her best friend, was supported by 24 h care in his home and Catherine’s brother lived in a care home; but they both described a range of activities they performed which contributed to the well-being of the person with MS.

A wider form of activism on behalf of a larger constituency of carers was, for some, part of the repertoire of tasks they took on to support people with MS. Some participants worked with, or established, groups or campaigns as a way of being involved in fundraising or raising awareness of MS and carers needs. Several people had taken on formal administrative roles in local MS support groups or carers organisations. One person set up a group, named after her son who had died with MS, to raise awareness of MS in the black community. One man campaigned politically for the continuation of Carer’s Allowance beyond the age of 65.

#### Caring identities

Most people who spoke about caregiving activities and tasks took them on willingly, even when it was difficult, as part of their relationship with the pwMS; but they did not all think of themselves, or describe themselves, as a ‘carer’, even when they talked about caring. Melvyn said he was ‘caring, but not a carer’; Tom and Jim described themselves as husbands rather than carers. Karen and Patricia both called themselves ‘wives’, not ‘carers’ (despite Patricia’s activism on behalf of carers). A number of people said their spouse would do the same for them if ‘the boot was on the other foot’ (Jack, aged 71, spouse profoundly disabled by secondary progressive MS), expressing a form of ‘virtual reciprocity’ or ‘hypothetical exchange’ (Boeije et al., 2003, p. 248; Nolan, Grant, & Keady, 1996). Others described themselves partially as carers; Edward and Ken both said they were sometimes husbands, at other times carers. A number of people had come to identify fully with the role of carer, some reluctantly and some with pride.

In this section, we elucidate the complexity and subtlety of what people said about caring identities, which included some apparent contradictions and some tensions. We describe four categories (which are not mutually exclusive) in which the identity of carer was apparently embraced, enforced, absorbed or rejected. Later, we consider these findings in the light of identity theory.

#### Embracing the identity of carer, concordant with other role identities

People can assume multiple identities simultaneously but there may be varying levels of concordance between those identities. For some of the people interviewed the identity of carer appeared to sit comfortably with other identities, irrespective of the caring tasks carried out (see Table 1). Those who described feeling proud of their role included spouses but also those who did not live with the person with MS or whose relationship might be considered more tangential to a caring role – for example, Alice who maintained a strong presence in the life of her ex-partner and ‘best friend’ who

has primary progressive MS and Catherine whose brother has secondary progressive MS.

*I do see myself as his carer. I’m very proud to be that, more proud of that than my day job...I’m there because I want to be there, because I love him and want him to be as happy as he possibly can be (Alice, aged 37, former partner with primary progressive MS, 24 h home care).*

*Yes, I do feel like my brother’s carer because I’m looking out for his best interests’ (Catherine, aged 38, younger brother with secondary progressive MS who lives in a care home).*

Neither Alice nor Catherine were responsible for giving physical care but regarded their active promotion of well-being in the pwMS, by giving emotional support and advocacy, to be part of a caring identity which complemented their identities as best friend and sister.

Terry’s wife, in contrast, was completely dependent on him and the caring services which he co-ordinated. ‘My approach to caring is now, after many years, it’s a job ... and if you take this approach it becomes easier’ (Terry, aged 71, spouse with secondary progressive MS). Alluding to the UK National Health Service (NHS) Expert Patient Programme (NHS Choices, 2010) Terry described himself as an ‘expert carer’ who had also been an active and leading member of organisations campaigning in support of people with MS. Terry gave no indication that any of this was in conflict with his identity as a spouse.

Clare described a relationship of mutual reciprocity and support in a caring context which had changed from giving ‘absolute care’ to providing emotional support:

*I have always been my husband’s carer. I will always be my husband’s carer. I may not care for him in the sense of now being the absolute carer for his day to day needs but I care for him in the sense that I give him the emotional support. We talk, we support each other and I think the caring mode is still there but it’s in a different context. So the care mode will always be there, it’s just changed from the day to day caring side to being the supportive caring side. And that will always continue until he passes on (Clare, aged 42, husband with secondary progressive MS who was diagnosed before their marriage in 1986).*

#### Enforced identity as carer, discordant with other role identities

Some people acknowledged that they were carers, but talked about struggles and tensions they experienced in occupying this role alongside others. Kathryn’s role had gradually changed and she said that she had ‘found it very difficult to function as a wife at the same times as being a carer’ to her husband with secondary progressive MS. She concentrated on giving practical rather than emotional support, having been through ‘a transition time when I was trying to do both equally well but [I] realised I couldn’t keep it up. And so I accepted in my heart that he needed a carer and it was more important for me to be that carer than anybody else.’ Kathryn (aged 49) said that taking on this role was her way of committing to her marriage. She added that ‘It looks very different from an ordinary marriage.’

Don indicated that his personal identity had become subsumed in caring for his wife with long-standing secondary progressive MS. His caring role was ‘expected’ and performed as a husband, but at the age of 73 he was aware that he could not anticipate many more healthy and independent years in his own life: *Your life changes when you become a carer, because you no longer think about you, but about the person you’re caring for...you’re expected to do it out of love and the problem is as you get older you get less capable of doing it and in the end it’s you who wants a carer.*

Barbara described herself clearly as a carer, and she had actively made a choice to take on a caring role for her partner of thirty years.



But she regarded the choice as one forced on her by circumstances and she described her dislike of the role and identity of carer in forceful terms:

*So I thought, "Right, that's it. I've got to become a carer." But I didn't know what it involved, I really didn't, because nobody tells you. And that's when it all sort of kicks in, the enormity of it. You're not given training at all. I think with something like MS you should be given training. I mean I didn't know the correct way to pick him up if he fell over [...] I've only found out through asking other carers [...] I don't know what else to say about caring. I absolutely hate it. I loathe it. And if I had lots of money I'd be more than happy to say, "Right, pay somebody, come in, you do it", but unfortunately I can't. And I'm like the majority of other carers (Barbara, aged 58, partner with primary progressive MS).*

#### *Absorbing a partial identity as carer: ambivalence and fluidity*

Defining oneself as a carer was not always straightforward. Some people quantified the time they spent in caring compared with other roles in relation to the pwMS. Edward, aged 65, whose wife was severely disabled by secondary progressive MS, described himself as changing from 'being a husband to being 75% a carer, 25% a husband these days ... My wife can't do anything so somebody's got to do it for her. It gets you down sometimes'. Ken pointed out that his role, and his identity, as a carer was fluid and was determined by his partner's condition on any given day.

*I would say it tends to vary because MS is quite a funny disease because one day she could be completely fine for a couple of hours and the next day she'd be very tired and so I couldn't say that I give sort of fifty-fifty one way or the other. Some days it might be seventy-thirty — seventy partner, thirty carer. Other days it might be the other way round. So it doesn't really stay stable, it sort of comes and it goes [...] I tend to do all the shopping, all the cooking, I've just fallen into that role anyway but that doesn't make me think of myself as being a carer. It's things like setting up cutlery and before I go to work I'll make coffee and leave it out and I'll set the breakfast things up. Things like that, I do feel like a carer on those occasions. But most of the time lately I've been sort of seventy per cent partner, thirty per cent carer. But there was an occasion where she went to hospital for two weeks, the week leading up to that when she had a relapse then I was ninety five per cent carer, five percent partner, so it varies depending on my partner's condition (Ken, aged 40, partner with relapsing-remitting MS).*

Sometimes the identity of carer was pragmatically adopted as a badge which helped signal to the world that part of your relationship with a significant person in your life involved giving informal care to that person. Matthew's personal identity in relation to his father remained that of 'son' but he also called himself a 'carer':

*I identify myself as a carer [but] it's just a title. I do it naturally so I'm not a carer, really, I'm just my dad's son looking after him. But if I'm speaking to somebody I'll say I'm his carer because that's what I'm doing. It's a role that I'm playing. I am his carer because if he needs anything, or he wants anything, he'll call me. If he's struggling to get on the toilet he'll call me. I look after his hygiene. If he's had an accident, he'll call me (Matthew, aged 35, father with secondary progressive MS).*

Unlike Matthew and some others, Laura did not describe herself publicly as a carer and she continued, partly, to resist affiliation with what she saw as a 'kind of miserable term'. In the following extract there is evident ambivalence about her developing identity as a carer:

*It is a tough call doing it, and your relationship totally changes. Whereas I was a wife, I do feel much more, you know, our relationship obviously, has changed and I am a carer and I suppose it's not*

*something that you, well, you want to admit to yourself or to other people, but it's a fact. Yeah, you're giving up one aspect of your life, your personality or whatever to be something that you haven't chosen to be and you are suddenly having to worry, you know, or do things that you'd never have thought you would have to do and it, you know, it is difficult. So first of all you think you won't do it. Well, certainly for me, I thought, "I won't be able to do that. I won't be able to care." But, actually, you do manage to. But you need to have breaks. I would say that, definitely [...] you need to have time for yourself. So I do have a very good network of friends and will go off and definitely have evenings out with them or, yeah, or a couple of days away if my husband can go off and stay with his family. And I think that's very important, so you're not just a carer (Laura, aged 42, husband with primary progressive MS).*

#### *Rejecting the identity of carer in favour of relational identity*

Paradoxically, most of those who apparently rejected the identity of carer described themselves as carrying out caregiving roles and some even acknowledged that, in other people's eyes, they were seen as carers; but they did not internalise this identity, preferring instead to define themselves in relationship-based categories (wife, husband, partner) to the pwMS. Melvyn, aged 50, made a distinction between 'caring for' his partner with aggressive relapsing-remitting MS and being her 'carer'. He acknowledged that he was caring, but preferred to 'hold on' to the identity of partner rather than carer. Maureen had married her husband knowing that he already had MS. She recognised herself in a caring role but preferred other identities:

*I know I am his carer but first and foremost I'm his best friend, secondly I'm his wife, thirdly I'm the chief around here and the one that does everything (laughs). So, no, I don't think of myself as a carer (Maureen, aged 63, spouse with secondary progressive MS).*

Patricia, aged 44, had also married a person with MS and forcefully rejected the word 'carer' as a description of herself in relation to her severely disabled husband. Despite her active roles in advocating for his needs and as a spokesperson on behalf of carers, Patricia insisted that she is a 'wife'. Karen also identified herself firmly as a spouse and not a carer:

*When people say to me, "You're his carer", I say, "No, I'm not, I'm his wife." We don't look at this as caring at all. I didn't marry my husband to care for him. We married because we loved each other, not to care for each other....He would do a lot more for me if he could, I know he would (Karen, aged 75, husband with unspecified form of MS).*

Derek, uniquely among the people who spoke to us, did not identify himself with any of the roles he occupied, which included full-time work, household tasks, parenting and periodically supporting his wife with personal care. He presented his personal identity as 'just Derek' at the core of all this activity:

*I don't see myself as being a carer as such. S. looks after herself most of the time. It's only when she's really struggled to do things that I've helped. I do all the washing, cleaning, stuff like that, just the things that you have to do to keep the household going. But I don't think of myself as a carer, just Derek doing all this stuff (Derek, aged 53, spouse with relapsing-remitting MS).*

## **Discussion**

Family members and friends adopted the identity of 'carer' to different degrees. Some embraced the identity of carer, incorporating it readily into their repertoire of roles. Others acknowledged the identity of carer but felt that it was forced on them by circumstances

and that it was discordant with their preferred identity. For some participants the identity of carer had been absorbed gradually over time and was fluidly related to the caring tasks they undertook. Some people firmly rejected the identity of carer, even when they acknowledged that they performed caring activities, preferring an identity based on their relationship with their relative or friend with MS. Other research, in the UK and Canada, has also shown that relatives' identification with the term 'carer' is variable (Bowen et al., 2011; O'Connor, 2007).

With regard to role-based identity, both identity reinforcement and identity conflict (Stryker & Burke, 2000) can be seen in the findings we present. Some participants described themselves as engaging in caregiving acts (nurturing, helping, supporting) but situated their behaviour in a role identity that is different from the role of 'carer'. In some cases the role of spouse continued to be the prominent part of the person's expressed identity in relation to the pwMS; in others, the individual's personal identity was dominant. For some participants multiple identities seemed to reinforce each other. From the perspective of social identity theory, membership of carers groups or voluntary societies (typically, the MS Society) could reinforce the identity of carer even where the role was embraced but disliked.

There was personal and role conflict for some in the experience of making a transition into the role and identity of carer. The decisions to perform caring roles and to identify oneself as a carer were sometimes influenced by a sense of obligation to a partner with MS (Boeije & van Doorne-Huiskes, 2003) but these decisions did not always resolve self-conflict, particularly where there was intense dislike of the caring role. For some people self-identification as a 'carer' did not seem to arise from a genuine choice (Nolan, 2001, p. 32). Others seemed more readily to integrate the identity of carer into their repertoire of role identities, wearing the badge of carer with some pride and harmonising their efforts with those of professional caregivers.

The identity of carer was externally ascribed in some cases to relatives of people with MS, particularly where they lived with a spouse or partner (Mutch, 2010) and received welfare benefits specifically directed at carers. Some internalised the identity of carer and some did not. In a study of the experiences of family caregiving among middle-aged Australian women, Lee and Porteous (2002) argued that some women internalised an 'ethic of care' whereas others, like Barbara in our study, perceived the role of carer to be 'imposed against their will by broader social systems that were hostile to their personal needs' (p. 90).

In a study examining the gendered nature of caregiving, Calasanti and King (2007) argued that their sample of men in the USA 'embodied a style of caregiving that focused on tasks characteristic of occupationally based masculinity' (p. 518). That is, like Terry and Peter in our study, they treated caring as if it were a job in which they could achieve 'mastery' in a way that was consistent with their personal identity. Calasanti and King (2007) argue that men experience less stress than women in the role of caregiver by this strategy of 'taking women's work like a man'. Earlier US research suggested that for women, particularly spouses, informal caregiving may be an unwanted and resented continuation of a job they have been doing for most of their lives. 'Engulfment' in this role made women more susceptible than men to 'loss of self' (Skaff & Pearlin, 1992). It may be that cultural expectations about who should care, which vary across societies and generations — married women, wife of eldest son, unmarried daughter, men and women taking equal share — affect both self-identification with and acceptance of the role of informal caregiver.

Some participants in our study presented a fluid identity in which they expressed a partial affiliation with the role or position of carer, depending on the specific type of support they were giving to

a pwMS at particular times. Some people assumed and expressed multiple identities at the same time, without any real sense of contradiction, but sometimes in a hierarchy of affiliation — that is, they acknowledged themselves to be carers but preferred to see themselves in a relationship-based role as son, spouse or partner.

The role of carer might be self-ascribed but not confirmed or ratified by external markers (De Medeiros, 2005, p. 4) such as receipt of welfare benefits. Some caring roles involved time-laden activities, but not of the kind that qualified people to receive the UK benefit of Carer's Allowance, for example. As Lloyd observed (2006, p. 946), 'Whilst caring is a widespread activity, only a minority are eligible for state support.' The type of caring activity, not just its duration, could also affect external ratification of the self-ascribed role of carer. The configurations of caring activities that individuals performed were very variable; from 'absolute' caring — which might encompass a very wide range of tasks — to activities that might look, to outsiders, like something else (e.g. friendship). Providing emotional care and friendship to a pwMS that you did not live with would not likely bring recognition as a carer, either from the welfare system or from paid caregivers. As Stryker and Burke (2000 p. 289) put it, 'Identities may or may not be confirmed in situationally-based interaction.'

### *Strengths and limitations of the study*

The heterogeneity of the study sample, including people in a wide range of familial and social relationships to people with MS, allows a different light to be shed on what it means to be a 'carer'. The combination of open narrative and semi-structured questioning in the interviews enabled a rich dialogue in which participants could express their experiences and views relatively unconstrained by preconceptions about what researchers would want to hear. Of course, the interview was a one-time event and participants may have responded differently on a separate occasion or to another interviewer. Our interpretations should not be taken to represent the whole of any participant's point of view. But, the variability of perspective in the accounts we report indicates that the designation of informal caregiver is not straightforward and should not be taken for granted.

### **Conclusion**

Variability and fluidity in self-identification as a carer may be related to other people's expectations about whether one *should* assume the caring role — those who were caring from the more tangential (and less taken for granted) relationship of sibling or ex-partner were among those who embraced the role and the identity of carer. Those who are expected (typically spouses) to assume the caring role will not always be comfortable with doing so and may resist both the role and the label. Young carers may have little choice about occupying the role of carer, which may have a significant impact on their developing personal identity.

Others may accept the role of carer but resist the label if they see it as a 'bureaucratisation' of their personal relationships (Foster, 2005) which imposes on them an unwanted identity. It may be that people respond differently to the noun 'carer' compared to the verbal forms 'care' or 'caring'. Whilst 'caring' can encompass a range of relational meanings (including affection and nurturing as well as physical tasks undertaken for the person one cares for or about), the noun 'carer' risks imposing a more transactional and bureaucratised meaning. 'Caregiver' as a noun also implies a one-way transaction rather than mutual exchange. It is possible to be a carer without actually caring; it is also possible to care for or about someone whilst rejecting the concrete noun 'carer'. If the identity of caregiver is rejected, by people who nevertheless occupy the role of

carer, and see themselves as caring, then informal caregiving may continue to be hidden and potential sources of help and support may remain under-utilised. As Neufeld and Harrison (2003) argue, in a Canadian context, health and social care professionals need to 'assess caregivers' personal expectations and the salience of their caregiving identity' (p. 330) in order to help them get support.

Increasingly, though, it may be that people will extend their overt, conscious adoption of multiple and fluid identities to include the identity of carer if this affiliation helps them to gain new understandings of their lives, to gain various forms of aid or to participate in networks of support (O'Connor, 2007). People may tolerate the bureaucratisation of their personal relationships in exchange for something which acknowledges and rewards the effort and costs of caregiving, however it is conceptualised or labelled. Rewards are not always monetary — there is intrinsic value in caring 'above expectations', as demonstrated by these interviews, especially those with men and non-spouse carers. There would likely be major challenges in continuing to provide supportive services which meet peoples' expectations if a single term whose meaning is broadly understood were to be abandoned, so it remains to be seen whether a new term will emerge (Molyneux et al., 2011) that can capture more fully the subtlety and variability of this relationship-based role.

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